

State Plan 2001: Blueprint for Change

Consumer and Family State Plan Advisory Committee Report

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Introduction

During the initial development of the State Plan, consumers and family members were asked to comment about their experiences in the service system. A Consumer and Family State Plan Advisory Committee was formed, and its recommendations are outlined in this document.

Consumers and family members will continue to be important voices as the State Plan evolves. The State Plan ensures:

- Consumers and family members have a substantive role in planning, management and oversight of the system.
- Consumers and family members have a major role in developing methods for identifying and filling gaps in services.
- Consumers and family members have a meaningful role in developing strategies for engaging other consumers and families in implementing the State Plan and local business plans.

Two important mechanisms for ensuring the ongoing involvement of consumers and family members in the implementation of the State Plan are the formation of the Office of Consumer Affairs and of Consumer and Family Advisory Committees.

Office of Consumer Affairs

The Division will establish an Office of Consumer Affairs. The office will be lead by a consumer who reports directly to the Division director and is a member of the Division's management team. Staff in this office will include a designated position for each of the service groups served through the Division and administrative support.

State and Local Consumer and Family Advisory Committees

The Division will convene a state-level consumer and family advisory committee and will require each local management entity (LME) to convene a consumer and family advisory committee. The composition, staffing and recruitment of members, and the timing and links to other entities shall be as follows:

- Membership will be 100 percent consumers and family members.
- People representing all disability groups will be equally represented.
- Race and ethnicity of members will be representative of those who are served by the system.
- Each committee will have for each disability group, a man, a woman and a youth member. Family members may represent children. A parent may represent the needs of parents of adult consumers but shall not represent adult consumers.
- The Office of Consumer Affairs coordinator will staff the state advisory committee.
- The Office of Consumer Affairs coordinator will recruit the initial members of the state advisory committee.

- Each local advisory committee will be staffed by an employee of the LME whose responsibilities will include obtaining consumer and family input from the community; implementing recommendations of the advisory committee, and serving as liaison to the state advisory committee and other local agencies, organizations and associations. This staff person will recruit the initial members of the local advisory committee in collaboration with local consumer and family advocacy organizations.
- The committees will be created prior to the development of local business plans.
- State and local advisory committees will have clearly specified relationships to one another and to state and local consumer advocacy programs, human rights committees and the Governor's Advocacy Council for Persons with Disabilities.
- Local committees will have clearly specified relationships to county/area boards.
- Advisory committees will help educate elected officials and advocate for funding.

The roles of the state and local advisory committees regarding local business plans:

- Local committees will approve the local planning process and will review and submit to the state their own reports on local business plans.
- The state committee will review local plans and local committees' reports on plans and will make recommendations regarding state approval of local business plans.

The roles of the state and local advisory committees in ongoing planning, management and system oversight:

- Review and advise regarding long term and annual state and LME plans.
- Provide recommendations regarding service eligibility and service array, including:
 - identify gaps in services,
 - identify underserved populations,
 - advise regarding development of additional services, and
 - monitor service development and delivery.
- Review and monitor the state's budget for services and LMEs' budgets.
- Monitor the state and LMEs implementation of State Plan and local business plans.
- Educate state and local elected officials and advocate for funding.
- Review and advice regarding outcome data collection.
- Monitor tracking and reporting of outcomes.
- Monitor activities undertaken to improve quality.
- Ensure consumer and family participation in all quality improvement projects.

The Division and LMEs will support state and local Consumer and Family Advisory Committees, as follows:

- Stipends as appropriate to ensure participation.
- Transportation or compensation for travel.
- Childcare and eldercare if needed.
- Flexible scheduling of meeting times.
- Information and education regarding the service system:

- User-friendly primer regarding existing system and funding sources.
- List of the services that are available and how to access them.
- Materials regarding model systems and best practice services/supports.

Methods for Getting Input for the State Plan

Consumers and family members comment was gathered in a number of ways. A community services survey was distributed widely and used as basis for consumer and family member focus group discussions. Focus groups included individuals from throughout the state.

A special effort was made to ensure diversity among individuals providing input. The views of those who historically have been less involved in shaping the system of services were obtained. These groups included African-Americans, Hispanics/Latinos, Native Americans, and people who are deaf or hard of hearing.

Consumer and Family State Plan Advisory Committee

Recommendations

The following recommendations were made by the Consumer and Family State Plan Advisory Committee to ensure involvement of consumers and family members in ongoing system planning, management and oversight.

Recommendation 1. Immediately add three positions for consumers and family members to the Secretary's State Plan Advisory Committee. This recommendation was accepted and immediately implemented by the Secretary.

Recommendation 2. Continue and improve the current mechanisms for ensuring consumer and family involvement. Many boards, committees and councils have consumer and family representation that is mandated by state or federal laws. These relationships should continue, with one important change – information, education and support should be provided as needed to ensure that consumers and family members can participate effectively.

Recommendation 3. Establish a state Consumer and Family Advisory Committee and require LMEs to establish local Consumer and Family Advisory Committees. This recommendation was approved and details are provided earlier in this document.

Recommendation 4. The Division and LMEs should provide meaningful support to members of Consumer and Family Advisory Committees. This recommendation was approved, and details are provided earlier in this document.

Recommendation 5. LMEs should have a clearly defined planning process to get input from consumers and families about the service system – especially about service gaps. LMEs

should provide consumers and families with a comprehensive description of services that could be available.

Potential consumers also must be involved in the local planning process. It is recommended that the following agencies be included in identifying gaps in services since their staff members are often knowledgeable about potential consumers:

- Criminal justice (police, sheriff, probation officers, juvenile justice)
- Homeless shelters
- Schools
- Department of Social Services
- Public Health
- Faith communities

Consumers and families could have local input into the LMEs' planning efforts through public forums, short surveys with follow-up phone calls, focus groups and toll free telephone lines.

It will be very important to provide consumers and families with information about how to become involved in the local planning effort. Ways to provide input should be well advertised and include use of flyers, public service announcements, billboards and Internet notices. Notices should be placed across the community including provider offices, departments of social services, health departments, schools, libraries, and buses.

Recommendation 6. The Division should establish an Office of Consumer Affairs. The office will be headed by a consumer reporting directly to the Division director and is a member of the Division's management team. Staff of the Office of Consumer Affairs should include a designated position for each of the disabilities and administrative support.

Recommendation 7. The Division and LMEs should examine data to identify possible disparities in access to mental health, developmental disabilities and substance abuse services and disparities in consumer outcomes for the following areas: race/ethnicity, gender, sexual orientation, age, disability, geographical location, income and educational level. Strategies should be developed to eliminate the disparities and a report on progress in eliminating disparities should be provided annually to the state and local consumer and family advisory committees.

Recommendation 8. The issues described on the following pages should be given high priority in the redesigned system:

Service/Support Gaps to Be Filled

Substance Abuse	<p>Appropriate care requires a full continuum. Gaps mentioned most often:</p> <ul style="list-style-type: none"> • Long-term recovery services • Residential services • Services for adolescents • Services for women, especially those with children • Services in rural areas
Child Mental Health	<ul style="list-style-type: none"> • School-based services • Home-based services • Better access to psychiatrists • Case management • Respite services
Adult Mental Health	<ul style="list-style-type: none"> • Fountain House model clubhouses • ACT Teams • Integrated treatment for people with mental illness and substance abuse
Developmental Disabilities	<ul style="list-style-type: none"> • Dependable in-home services by qualified staff • In-home respite (especially in rural areas) • Family supports, including education needed to support family members with developmental disabilities upon request • Residential options • Day programs, especially for those transitioning out of school • Supported employment that is not facility based
Hispanic/Latino Consumers and Family Members	<ul style="list-style-type: none"> • Treatment for depression • Treatment for anxiety and stress caused by being in another country • Alcohol and drug treatment

Improve Access to Services

Substance Abuse	<ul style="list-style-type: none"> • Improve timeliness/eliminate waits • Make information about services widely available
Child Mental Health	<ul style="list-style-type: none"> • Improve timeliness • Make access easier
Adult Mental Health	<ul style="list-style-type: none"> • Toll-free access to after hours crisis services • Information about access to crisis services widely available • Eliminate long waits in mental health center waiting rooms • More frequent access, especially to psychiatrists
Developmental Disabilities	<ul style="list-style-type: none"> • Make information about support options available to families • Access to CAP should be based on need • Improve timeliness (especially when replacement staff are needed due to staff turnover; during a crisis; and obtaining needed equipment)
Hispanic/Latino Consumers and Family Members	<ul style="list-style-type: none"> • Provide information in Spanish about problems and that they are treatable • Provide information in Spanish about how and where to get services • Make access easier; get rid of answering machines; return calls • Hire staff who speak Spanish • Make services affordable to people who don't have Medicaid

Provide Appropriate Care

Substance Abuse	<ul style="list-style-type: none"> • Strengths-based services • Individualized services • Good assessments • Long-term supports
Child Mental Health	<ul style="list-style-type: none"> • Family participation, with supports for families (support groups, information) • Inter-agency collaboration • System of Care principles followed statewide • Strengths-based services • Consultation to and education of teachers
Adult Mental Health	<ul style="list-style-type: none"> • Peer Support • Services/supports that focus on recovery • ACT Teams • Integrated treatment for people with mental illness and substance abuse • Educating consumers about their illnesses, medications and side effects • Staff who listen and respect consumers' views about their needs • Continuity of Caregivers, especially psychiatrists
Developmental Disabilities	<ul style="list-style-type: none"> • Individualized supports for consumers • Supports for families, including education upon request • Continuity of caregivers • Choice/flexibility
Hispanic/Latino Consumers and Family Members	<ul style="list-style-type: none"> • Involve families • Have services provided by staff who speak Spanish • Provide education in Spanish using videos, reading materials

Staff Training Is Needed To Improve the Following

All Disabilities	<ul style="list-style-type: none"> • Customer service/interpersonal skills • Serving consumers with multiple disabilities (MI/MR/SA)
Substance Abuse	<ul style="list-style-type: none"> • Performing accurate assessments • Knowledge about substance abuse • Cultural competence
Child Mental Health	<ul style="list-style-type: none"> • Providing services for children and families • Cultural competence
Adult Mental Health	<ul style="list-style-type: none"> • Providing best practice services/supports • Ability to value consumer views and listen effectively • Cultural competence
Developmental Disabilities	<ul style="list-style-type: none"> • Providing information to families about available options • Ability to appropriately support people with cognitive disabilities, especially those who are deaf, autistic, blind
Hispanic/Latino Consumers and Family Members	<ul style="list-style-type: none"> • Cultural Competence • Ability to identify people with problems and help them

Staff Attitudes/Capabilities Appreciated/Desired

All Disabilities	<ul style="list-style-type: none"> • Respectful • Caring • Build trusting relationships – with consumers and with families • Open
Substance Abuse	<ul style="list-style-type: none"> • Non-judgmental, non-blaming • Patient • Have a sense of humor
Child Mental Health	<ul style="list-style-type: none"> • Respectful of parents' knowledge of their children
Adult Mental Health	<ul style="list-style-type: none"> • Work in partnership with consumers • Give consumers choices • Good listener
Developmental Disabilities	<ul style="list-style-type: none"> • Dependable (especially, in-home workers show up, and on time) • Case managers provide timely follow through • Staff keep family informed • Committed
Hispanic/Latino Consumers and Family Members	<ul style="list-style-type: none"> • Kind • Dynamic • Less strict • More understanding